DOCUMENT RESUME

ED 175 186 EC 120 041

AUTHOR Rosenfeld, Anne H.
TITLE Parents as Cotherapists with Autistic Children. Parent-Child Program Series, Report No. 3.
INSTITUTION North Carolina Univ., Chapel Hill.
SPONS AGENCY National Inst. of Mental Health (DHEW), Rockville, Md. Center for Studies of Child and Family Mental Health.
PUB DATE 78
CONTRACT TOPLD-13691-76
GRANT MH-15539
NOTE 15p.; For related information, see EC 120 039-043
AVAILABLE FROM Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402 (Stock No. 017-024-00840-1)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Autism; *Child Development; Clinical Diagnosis; *Home Programs; Parent Child Relationship; Parent Education; *Parent Participation; *Preschool Programs; *Psychotherapy
IDENTIFIERS *Child Research Project

ABSTRACT

Part of a series on early childhood demonstration programs designed to improve early parent-child relationships, stimulate positive child development, and prevent later behavior difficulties, the pamphlet describes the Child Research Project at the University of North Carolina, in which parents were trained to act as cotherapists with their autistic children. On the basis of a diagnostic evaluation, professional staff devised an individualized treatment program plan consisting of outpatient psychotherapy at the treatment center and the training of parents to continue the therapy with the child at home. The rationale for this parent participation is presented, and the diagnosis and assessment aspects of the program are discussed. Also reviewed are both the clinical and home treatment components, parent group meetings, program staffing, and special facilities and resources. Program graduates were found to retain many benefits, though the rate and type of progress of individual children depended, in part, on the severity of their initial biological handicaps. Many showed sufficient lessening of their psychotic symptoms to attend school, though they retained some minor behavioral problems; and some showed dramatic gains in intellectual functioning. (DLS)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Parent-Child Program Series

National Institute of Mental Health

Report No. 3

Parents as Cotherapists With Autistic Children

ED175186

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

EC120041

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Public Health Service

Alcohol, Drug Abuse, and Mental Health Administration

Parent-Child Program Series

Report No. 3
Parents as Cotherapists With Autistic Children

NIMH Grant: MH 15539

Program Developers: Eric Schopler
Robert J. Reichler

Sponsoring Institution: University of North Carolina at Chapel Hill
Chapel Hill, North Carolina

Science Writer: Anne H. Rosenfeld
Contract No. TOPLD-13691-76
From the National Institute of Mental Health

Center for Studies of Child and Family Mental Health
National Institute of Mental Health
5600 Fishers Lane
Rockville, Maryland 20857

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, D.C. 20402
Stock Number 017-024-00840-1

Preface

Families and Professionals as Partners pamphlets represent an effort on the part of the Center for Studies of Child and Family Mental Health, National Institute of Mental Health, to make visible successful models of programs which enable families to play an important role in improving child mental health. Each pamphlet describes a practical program that can be adapted to local community needs. The present Parent-Child Program Series of five pamphlets describes demonstration programs involving young children from infancy through preschool. The general goals of the series include improving early parent-child relationships, stimulating positive social-emotional development, and preventing later behavior difficulties. This reflects the center's goal of encouraging the utilization of recent research findings by service providers and families to help improve child mental health in their communities.

Joy G. Schulterbrandt
Chief
Center for Studies of Child and Family
Mental Health

PARENT-CHILD PROGRAM SERIES

Introduction

Our Nation's children are a precious but often underdeveloped natural resource. Since the 1960's, social conscience and new scientific insights have converged to spark exploration and demonstration of many new ways to enhance the early years of childhood. Spurred by child development research that marked the preschool years as the cornerstone for subsequent cognitive and emotional development, a number of action and evaluation programs have begun with Federal funding to discover effective ways to stimulate psychological growth in infants and young children. Although many of these programs have been geared toward children from poverty backgrounds, they can help in better development for all children. Head Start, Follow Through, and Sesame Street are among the most famous of these large-scale programs.

Less familiar, perhaps, has been another line of exploration; although more modest in scope, it is comparable in developmental impact: educating parents to work and play with their young children so that their youngsters may grow as thinking, feeling individuals. Many of the programs have been sponsored by the National Institute of Mental Health, which has long recognized that starting children at a very early age on the right developmental footing may prevent later emotional and intellectual problems.

More than a decade of experiment and study has yielded a wealth of parent-involved programs for early childhood enrichment. Their efficacy is well documented. They work—and they can work in new settings and communities as well. The question now is: Will we let them work? Are there people who care enough about children in their own communities to carry these programs forward? We have made great strides as a Nation in providing better opportunities for children to grow up physically healthy. But, for all too many preschoolers, critical formative years are passing without the stimulation and guidance required for healthy emotional and mental development. As innumerable experimental programs have shown, parents can become eager and able teachers of their infants and children once they have learned how to translate their caring into skills and attitudes that actually help their children to develop. Many parents tend to underestimate their young children's abilities because they do not know how to bring them out into the open.

Good parenting does not come automatically with the birth of a child—or even many children. It is a skillful activity that, for many, takes some training. How to provide that training—in a number of different settings and for somewhat different children—is the subject of this series of pamphlets.

The approaches to parent training reported here grew out of research-demonstration programs supported by the National Institute of Mental Health. Having demonstrated their feasibility and worth, these approaches are now ready for use wherever there are communities willing to make a modest investment that may pay big, long-range dividends for their children. The specific training programs are for the most part relatively simple and inexpensive to implement, and they are likely to offer rich rewards not only to the children but to their parents as well. Because the skills parents acquire are easy to transmit, these programs potentially have a snowball effect: each parent trained may transmit skills to other children and parents. Once a program has been established, recruitment is often unnecessary. Enthusiastic parents spread the word to others. Over and over these programs have met with great parent support because they provide them with the deeply gratifying ability to help their children make visible progress at home, and later at school—often far more than parents thought possible.

This report provides an overview of one approach to parent training, but only its highlights. More detailed information is available. We will describe the program as it was carried out in its original setting as a research-demonstration project, but, as you will see, many variations on the theme are possible, depending on local community needs and resources.

Parent training programs are no panaceas. But they represent needed ways to start young children on the right developmental path—stimulating their curiosity, rewarding their explorations and little triumphs, guiding mind, hand, and eye, indeed the whole child, toward greater understanding, confidence, and competence. Both parents and their young children can learn a form of communication that enriches and delights.

Parents as Cotherapists With Autistic Children

In almost every community in our country there are very young children who suffer from serious problems of communication and development. These youngsters may behave in quite different ways, but they evoke similar reactions of puzzlement, frustration, and guilt in their parents. In one family, perhaps, a youngster is mute and unreactive, seemingly deaf, although hearing tests have proven normal and some sounds seem to startle him. In another, a child seems like a manic butterfly, fluttering from one frenetic activity to another—sometimes even flapping his arms—never settling down long enough to interact meaningfully with other people. In yet another home, a child may be extremely passive and inert, the daydreamer transported to an imaginary place. His only motion is rocking rhythmically, as if it helped him gallop away from the present.

Until fairly recently, such children, often diagnosed as having childhood psychosis or autism, were regarded as the tragic victims of an incurable illness; lifetime institutionalization was often their lot. We now have many ways to help some of these children so they can remain at home, attend school, and function relatively normally. But often too few trained professionals are available to provide the kinds of intensive help these children need.

An NIMH-sponsored research-demonstration program, the Child Research Project at the University of North Carolina, has yielded an effective way to extend professionally staffed treatment programs for autistic and communication handicapped children by using the children's parents as cotherapists. The idea has proven so successful that in 1972 it was adopted for use on a state-wide basis in North Carolina and has evoked extensive national and international interest. An expanded model includes five centers and 20 special education classrooms in the public schools which permit special education teachers and parents to work together to help school-age children with similar handicaps to function more effectively.

The basic plan of the original program is this:

- Parents and their autistic or psychotic child come to a professionally staffed center where the child's behavior (both alone

and with his parents) is observed, his strengths and weaknesses identified, and his problem diagnosed.

- On the basis of the diagnostic evaluation, the professional staff members devise an individualized treatment plan with two major components: a *treatment program* to be carried out at the center on an outpatient basis by trained staff, with parents as observers; and a *home program* to be carried out by the parents working with their child regularly between visits to the center.
- Parents and staff members meet regularly for training and supervision to help parents acquire the skills and confidence required to work effectively with their own child. Parents learn by watching professionals interact with their child, by receiving supervision of their own demonstrated behavior with their child, by discussing child management problems with staff, and by sharing problems and possible solutions with other parents in the program at regularly scheduled parent group meetings.

The initial demonstration project yielded dramatic improvements in some children and more modest, but significant, gains in many others. Research studies are still underway to identify ways to make the program even more effective in the future. Let us now look at the program in greater detail, focusing particularly on several innovative features which, having contributed to its initial success, should lend themselves to adoption in other settings and communities.

Parent Participation: Rationale

The idea of having parents work with their own disturbed children is so simple, obvious, and natural that it is hard to realize what a radical suggestion it represents to some child experts. For many years, Freudian therapists have viewed cold, rejecting parents as a major factor in the development of childhood psychoses. Naturally, many child therapists were more inclined to separate autistic children from their "schizophrenogenic parents" (especially mothers) than to encourage greater closeness and parent participation in their care. More recently, there have been many other approaches to the causes and treatment of childhood psychoses. Many experts, including Dr. Eric Schopler, the child psychologist who initiated the North Carolina project, and Dr. Robert Jay Reichler, the child psychiatrist who codirected it, now believe that childhood psychosis or autism more often stems from inherent biological problems than from "refrigerator" parents. That is, the children's strange behavior arises because their nervous systems process sensory information improperly. Their parents are no more to blame than the parents of blind, deaf, or mentally retarded children although, of

course, parental reactions to their children's handicaps can augment or minimize the children's problems.

In studying the parents of autistic children, Drs. Schopler and Reichler have found them to be essentially the same as any other parents, although clearly more puzzled by their youngsters' often bizarre behavior. Further, these investigators have found consistent evidence that children diagnosed as autistic may suffer from identifiable perceptual problems that may underly and account for their disturbed and disturbing behavior.

In short, in the opinion of these investigators, parents have too long been blamed and ignored, when, in fact, they have an important contribution to make to their own child's recovery. The results of the demonstration program initiated by these investigators have borne out their expectations. Parents were not only able to learn to be good and effective therapists with their own children—they were often more effective than the professionals! As Dr. Schopler has noted:

> Professionals may have a lot of information about many children, but the parents are really the experts on their individual child and his problems.

Diagnosis and Assessment

Youngsters with childhood psychosis or autism are often hard to diagnose, since their behavior mimics that of many other conditions. Many appear to be deaf, and others seem to be severely mentally retarded, although some show signs of extremely high intelligence. Even knowing that the child is autistic does not necessarily provide clues to appropriate treatment, since there is no universal magical pill or cure for autism. At best, today's treatment often consists of carefully identifying a given child's particular capabilities and needs; attempting, through careful retraining, to develop skills to compensate for those that are impaired; and guiding the child through developmental cycles and stages he might, if unaided, never attain.

Typically in the North Carolina program, considerable time is spent determining a child's particular problems and therapeutic needs before a treatment program is instituted. Children believed to be autistic or psychotic, who are functioning at preschool age levels, are referred to a center where they and their parents spend at least half a day while several types of diagnostic information are gathered. Parents supply history and background information in advance and, at the session, discuss past and current concerns with a therapist acting as a "parent consultant." The child is seen by a therapist and undergoes diagnostic tests, including one developed

by Drs. Schopler and Reichler to determine the child's degree of psychosis and impairment. The child's play interaction with his or her parents is also observed (through a one-way mirror) and rated.

To determine the child's level of development and educational potential, these investigators use another diagnostic test, the Psychoeducational Profile (PEP). It explores many aspects of a child's functional capabilities, including socio-emotional development, language, imitation, motor development, sensory and cognitive functions, and pathological behavior. In administering the test, a trained evaluator observes how the child responds to a standardized set of toys and play activities and then rates the child's behavior according to a unique scoring system. For each task posed by these toys, such as opening and using a jar of bubbles, or putting together a puzzle, there are three possible levels of achievement: passing, emerging, or failing. The novel "emerging" category permits the rater to identify areas in which the child understands what to do, but cannot do it successfully or requires repeated demonstrations before he or she is successful. Developmental areas identified as "emerging" later become the focus for parents' home therapy with their children.

An extended 6- to 8-week diagnostic period follows the initial testing session and permits staff, parents, and the child to know one another better and develop a realistic notion of their respective roles and potential. Research study of the program's impact on children and their parents has shown this to be an important period in establishing therapeutic goals and in educating parents to understand and work with their children. Sometimes significant gains were seen in families who participated only in this phase of the program but did not continue through with treatment.

The Treatment Program

Psychotic children often have deficits in many essential areas of human functioning. Thus, the treatment program is designed to help them develop in all of these deficit areas, with particular emphasis on areas in which individual children uniquely need extra help. Overall treatment goals of the program include: making the children more attentive to humans in their environment; encouraging them to develop interest and pleasure in exploring and mastering toys and educational materials; helping them to become more competent in communicating with others; and helping them to integrate and coordinate sensory perception and motor activity

more effectively. Many of the techniques used to realize these goals, derived from both behavior therapy and special education, have been modified through the years as program staff have developed clinical and research data on effective treatment approaches.

Typically, a family accepted into the program is expected to come to the center weekly to attend 45-minute therapy sessions. While one therapist works with the child, the parent observes through a one-way screen in the company of another therapist functioning as a "parent consultant." Parent and consultant discuss the demonstration, exploring salient points and issues previously highlighted for discussion by the two therapists.

The therapy demonstration sessions often focus on specific techniques for dealing with particular behavioral problems and issues, such as gaining the attention of an unresponsive child, stimulating the child to imitate words and use them meaningfully, encouraging better hand-eye coordination, and motivating the child to greater exploration and self-directed activity.

The therapist, while working directly with the child, also serves as a model and teacher for the parent. But in this context, a therapist is not held up as some godlike creature magically able to transform a strange and uncommunicative child into a paragon of normality. Observant parents soon realize that therapists too may fumble, especially in their early contacts with psychotic children. As noted by Drs. Schopler and Reichler:

> By allowing the parent to see the therapist's struggles, frustrations, and occasional mistakes, the parents become less self-critical and are better able to assume responsibility for the bond with their own child.

The Home Program

The child's sessions with the therapist are strongly reinforced through regular "exercises" carried out daily at home with his parents. (Both parents are expected to work with their child in the home program, but, not unexpectedly, the mother's role is usually more extensive.) The home program, like therapy, is designed with the particular child's needs and abilities in mind; it is changed as the child progresses. Contributing to its design are several types of information: results of the PEP evaluation, the therapist's assessment of the child, and the parents' comments regarding behavioral problems. (As noted earlier, particular focus is given to developing aspects of the child's functioning which, according to the PEP evaluation, are somewhat marginal but "emerging.")

At the beginning of therapy, parents often require a very specific home program, which they often follow quite literally. Later, a more flexible relationship develops between the therapist and the parents, with considerably more parental initiative shaping the home program as parents become more confident and competent.

To help keep track of the progress of children in the program, parents are asked to keep a daily log in which they record changes in their child's responses to each section of the home program. Both parents also fill out a weekly rating of their child's progress in other areas of home life.

At regular intervals, parents are asked to demonstrate the home program exercises with their child while the therapist and consultant observe through the one-way screen. This way of demonstrating progress also serves as a means for giving parents additional professional support and supervision. Parents also obtain help in dealing with problems not directly addressed in therapy or the home program by meeting with their consultant during the biweekly therapy sessions. Together they might develop a strategy for, say, encouraging a child to sleep in his own bed rather than his parents'.

Drs. Schopler and Reichler report that, over time, parents often become highly competent therapists with their children, as the following anecdote illustrates:

> Many parents, especially mothers, have developed a degree of objectivity, investment, and skill found only in top-notch teachers. For example, recently the director of an educational program for autistic children visited the Child Research Project. She was observing an adult-child interaction. After a brief time of observation, she remarked that this was an unusually skillful therapist and wondered why the parents were not observing. She was gratifyingly astonished to learn that it was the mother herself who was working with the child.

Parent Group Meetings

While parents obtain essential guidance and support from the program's professional staff, they are also encouraged to help one another. A monthly parent group meeting provides an opportunity for parents to share experiences and to learn more about childhood psychosis and its management through films and discussions. During the original project, the parent meetings also became a significant vehicle for mobilizing parents to work effectively on behalf of their children in a number of new political programs particularly responsive to the needs of psychotic and other handicapped children (see page 10).

Program Staffing

As conducted by the Child Development Project, the service program required a professional staff of a psychologist and psychiatrist serving as codirectors, and three M.A.-level staff members serving as therapists. Drs. Schopler and Reichler have described the therapists' roles and backgrounds as follows:

> All staff members function both as therapists and parent consultants, though not usually with the same family. This dual role enables them to best maintain a balanced perspective on parent-child interaction. Their past training and experience may have been in the disciplines of education, psychiatry, psychology, or social work. They are selected for their interest and skill in teaching autistic children and their parents rather than for their professional identity. Experience with such children, enthusiasm, and willingness to learn have so far proven the best qualifications.

Other communities wishing to adopt this program may find that one M.D. or Ph.D.-level director is sufficient and will adapt the number of therapists to suit their own program's size. At least two therapists are required, however, since they work in pairs.

Special Facilities and Resources

A program such as the one described here could be carried out with very modest physical resources. It requires two adjacent rooms connected by a one-way mirror, but otherwise no special physical facilities. Separate spaces should be provided for diagnostic testing and interviewing, routine office and recordkeeping procedures, and parent-child waiting. Space is also required for the storage and display of play equipment used in diagnosis and therapy.

Program Impact

The original Child Research Project has had far-reaching impact in demonstrating the feasibility and effectiveness of parents as therapists for their own autistic children. An unforeseen but fortuitous outcome has been the mobilization of these parents to work not only *with* their children, but *for* them to expand community resources for autistic and communication handicapped youngsters.

In recognition of the program's outstanding accomplishments, in 1972, the American Psychiatric Association presented a Gold

Achievement Award "for the establishment of productive research on developmental disorders of children and the implementation of an effective clinical application."

Study of the program's effects on parents has shown that many desirable changes can occur. Drs. Schopler and Reichler report:

> Parents see how their child's confused perceptions tie in with troublesome behaviors; they recognize the child's need for gestural cues and repetition; and they show changes in attitudes and feelings such as self-confidence and acceptance of the child's handicap, and sensitivity to what skills and behaviors are ready to be learned by the child.

Organized effort by parents participating in the program led to the creation of a State chapter of the National Society for Autistic Children, operation of a summer camp program for these children, and development of a day care program. Parents successfully pressed for passage of State legislation to establish a statewide program for the Treatment and Education of Autistic and related Communication handicapped Children (known by the acronym TEACCH). As a result, the State of North Carolina now funds Division TEACCH, a network of diagnostic and treatment centers and special classrooms serving all autistic and communication-handicapped children in the State. It is modeled after the parent-involved demonstration project.

How does participation in the program affect autistic children? The Child Research Project reaped many benefits for its child participants. However, the rate and type of progress of individual children depended, in part, on the severity of their initial biological handicaps. Thus, many children showed sufficient lessening of their psychotic symptoms to attend school and appeared like "normal" children, although they retained some minor behavioral problems. While some children were too biologically impaired to overcome their intellectual deficits, others showed dramatic gains in intellectual functioning, with appreciable rises in IQ scores. One purpose of the program's ongoing research efforts is to improve the ability of therapists to predict the growth potential of individual children so that they, their parents, and therapists can work together realistically to fulfill it. Further study is also underway to identify precisely how changes in parents' understanding and behavior affect the progress of their autistic children.

For Further Information

Drs. Schopler and Reichler have written several articles describing their program and its impact on parents and children. They have also published their psychotic rating scale and a manual describing the administration and use of the Psychoeducational Profile (PEP). The following publications are recommended:

Schopler, E., and Reichler, R.J. Developmental therapy by parents with their own autistic child. In: M. Rutter (ed.) *Infantile Autism: Concepts, Characteristics, and Treatment.* London: Churchill Livington; Baltimore: Williams and Wilkins, 1971. pp. 206-227.

Schopler, E., and Reichler, R.J. Parents as cotherapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia.* 1:87-102, 1971. Also published in *Mental Health Digest, 3:17-20, 1971.* In: S. Chess and A. Thomas (eds.) *Annual Progress in Child Psychiatry and Child Development.* New York: Brunner/Mazel, 1972. pp. 679-697; In: A. Davids (ed.) *Current Issues in Psychopathology.* Monterey, Calif.: Brooks/Cole, 1973.

Schopler, E., and Reichler, R. J. *Psychoeducational Profile.* Chapel Hill: Child Development Products, 1976.

Additional information on the program and its research evaluation may be obtained by writing to:

Division TEACCH—Administration & Research
Trailer 18, Department of Psychiatry
University of North Carolina School of Medicine
Chapel Hill, N. C. 27514.

* U.S. GOVERNMENT PRINTING OFFICE : 1979 O - 283-944